

Community-engaged Research of Social Determinants of Health

Marissa Raymond-Flesch

California Street, Suite 500, San Francisco, CA, USA

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Abstract

The health of adolescents, perhaps more than in any other period of their life, is shaped by the social determinants of health (SDH). The constellation of SDH that disadvantages a specific group's health may also make members of that population unable or unwilling to engage in health research. To build a comprehensive body of knowledge about how SDH operate within a specific social context, researchers must design studies that take into account how various vulnerabilities and oppressions may affect people's experiences of being recruited, interviewed and retained in a study. In 2014, we initiated a prospective cohort study with Latino youth living in the agricultural area of Salinas, California. We began this study with the understanding that it was imperative to develop methodological strategies that actively addressed potential challenges in ways that were culturally responsive, community engaged and inclusive. In this article, we describe our approach to developing best practices in four key areas: 1) building community partnerships and engagement; 2) consideration of staffing and staff support; 3) engaging youth's perspectives; and 4) developing culturally appropriate research protocols. In our sample of 599 participants, nearly all youth identify as Latinx (94 per cent), half (49 per cent) have at least one parent employed as a farmworker, 60 per cent reside in crowded housing conditions, and 42 per cent have mothers who did not complete high school. Given these multiple vulnerabilities, we view a robust number of youth expressing interest in study participation, the willingness of their parents to permit their children to be enrolled, and the achievement of an ambitious sample target as evidence that our efforts to undertake best practices in community-engaged and inclusive research were well received.

Keywords: *community engagement, Latino youth, rural environment, social determinants of health, cohort.*

Introduction

Groups of people who are systemically marginalised within a society have poorer health outcomes than those who have access to safe living conditions, non-hazardous work, a living wage, and educational, health and social welfare institutions (Wilkinson & Marmot 2003). These types of resources are frequently considered to be ‘social determinants of health’ (SDH), a term that broadly encompasses ‘the conditions in which people are born, grow, develop, live, work, and age’ (Viner et al. 2012). Importantly, the constellation of SDH that disadvantages a specific group’s health may also make its members unable or unwilling to engage in research: residential mobility, fear of arrest, non-comprehension of a national language, or a lack of transportation can all be barriers to optimal health and to research participation (George, Duran & Norris 2014). This has the potential to more deeply entrench health inequities as populations that go unstudied cannot benefit from interventions, treatments and services tailored to their needs (Dodgson & Struthers 2005; Wilson & Neville 2009).

To build a comprehensive body of knowledge about how SDH operate within a specific social context, researchers must begin by considering how various vulnerabilities and oppressions may affect people’s experiences of being recruited, interviewed and retained in a study. For example, members of a population that have suffered threats of deportation may be wary of interacting with people from outside their community and thus be challenging to reach through standard recruitment and retention channels (Teedon et al. 2015). Likewise, a longstanding history of exploitation of low-resource communities by researchers who were not members of those communities could be another barrier to people’s willingness to participate (Cacari-Stone et al. 2014; Sudhinaraset et al. 2017) Wallerstein et al. 2014, Sudhinaraset, Ling et al. 2017. Such exploitation by outsiders can have a negative impact that reverberates far beyond the research study itself. For example, the disclosure of the infa-

mous Tuskegee Study of Untreated Syphilis in the Negro Male, conducted by the United States Health Service from 1932 to 1972, has been found to be correlated with ‘increases in medical mistrust and mortality and decreases in both outpatient and inpatient physician interactions for older black men’ (Alsan & Wanamaker 2018). A local population’s sense of distrust or wariness about exploitation can also arise in the context of community-based organisations if they are perceived as being overly accountable to political funding sources or other outside interests (Marwell 2004).

If populations underrepresented in research choose to enrol in a study, research or survey questions developed for mainstream populations may not resonate with them or adequately allow for their experiences, which may lead to discomfort, frustration or distress, as well as a perception among community members that research is unhelpful. A lack of consonance between a population and the questions being asked also could result in incomplete or poor quality data, and potentially an investment of funds in research that yields few results of interest or improvements in population health. Under these circumstances, the risk of further stigmatisation and negative labelling of communities through the research process is all too real, and a problem-based approach can create a pathologising lens for researchers that obfuscates the strengths of communities.

In this article, we discuss the A Crecer (‘To Grow’) study, which examines SDH among Latino youth living in an agricultural community. We undertook this study with the knowledge that factors which potentially make these youth vulnerable to poor health outcomes may also pose specific challenges to enrolling them as research participants. We therefore understood that it was imperative from the outset of the study to develop methodological strategies that actively addressed these challenges in ways that were culturally responsive, community engaged and inclusive. As we set ourselves to

this task, we interpolated our own identities in order to be reflexive about how members of this community would see us as 'outsiders', or different from them, as well as our shared experiences and commonalities. Within this article's authorship team (hereafter referred to as 'our team'), which was responsible for the design and leadership of the study, two of us identify as Mexican American and two as children of immigrants. Some of our families struggled to make ends meet during our childhoods, including by working in the agricultural field economy, while others of us had the privilege of financial security. Prior to attending college, a few of us lived in neighbourhoods or attended schools that experienced elevated levels of teen pregnancy and violence. None of us grew up in the community where we conducted our research, although one author has lived and worked there for over 30 years and another was raised in a similar community in California.

In designing our approach, we understood that the youth we sought to enrol in our study and their families would consider us to be outsiders, and therefore our methodological strategies needed to address issues of building trust and rapport. With this in mind, we generated a series of questions about best practices for conducting research with rural Latino youth that shaped our research development and implementation: (1) How can we best develop and strengthen community relationships and community engagement in the research? (2) What considerations are important when staffing our study, and how can we best support staff to do this work? (3) How can we engage youth's perspectives in this study? (4) How can we develop culturally appropriate research protocols?

Below we present the methodological strategies developed in response to these

Extensive training in research methods was provided to the A Crecer research staff. In-person sessions facilitated by San Francisco-based staff were valuable not only in terms of building capacity and skills among the

newly hired junior members, but also in providing opportunities for the junior members to share knowledge about youth in Salinas with the more senior members, and for team bonding. Trainings included topics such as ethics and adherence to Institutional Review Board protocols; effective recruitment techniques; quantitative interview administration; in-depth qualitative interviewing; adolescent development and health issues; SDH research; and how to provide facilitated referrals for distressed participants. Several presentations of local public health data by Monterey County Health Department staff strengthened knowledge of adolescent health inequities. Trainings were ongoing and responsive to the needs of the junior research staff. For example, when staff members remarked that numerous participants were worried about firearm incidents that had taken place in town, an adolescent health physician from the research team (Marissa Raymond-Flesch) conducted a session on techniques for supporting youth exposed to violence and self-care for staff working with vulnerable youth.

Incorporating youth's perspectives

The question, How can we engage youth's perspectives in this study?, has been central to A Crecer from its inception. As a means of learning about youth's perspectives early in the study, we convened eight focus groups with youth recruited from participating middle schools as well as from Salinas youth leadership programs. (Findings from these focus groups have been published elsewhere; see Raymond-Flesch et al. 2017) Recruitment for these groups was conducted using strategies developed with input from the Principal or Vice-Principal at each school, as well as the CAB. Information sessions, held on campus at lunch, offered students an opportunity to learn about A Crecer, sign up for a focus group and talk informally with members of the research staff.

To secure parental support for the focus groups, we solicited input from local implementers of family-based prevention programs and met directly with parents during regularly scheduled parent meetings at each of the middle schools where the focus group recruitment was to be conducted. At each parent group, the study staff introduced A Crecer and its objectives; modelled a focus group discussion with the parents, having them role play the activities that would be conducted with participants during the group; discussed parent permission approaches; solicited input on what parents saw as the greatest needs for youth in the community; and offered an interactive educational session on adolescent health issues at a future date. These presentations were either bilingual or conducted in Spanish. Each presentation was led by one member of the San Francisco-based team or the local Co-I and a bilingual and bicultural field coordinator who was from the Salinas community.

A total of 42 youth participated in the eight focus groups, which followed an innovative structure. Rather than posing questions to the entire group, youth were engaged in a series of activities aimed at generating conversation. In the first activity, participants used stickers to rank their relative agreement or disagreement with statements about family, gender and relationships (e.g. 'It is very important for a guy to get respect from others', 'A woman must be a source of strength for her family'). They were then encouraged to discuss why and how strongly they agreed or disagreed with each statement. In the second activity, participants drew maps of their community, with prompts to include their home, school, recreational areas and transportation methods, and to indicate places where they felt safe and unsafe. Participants then presented their maps to the group, indicating points of interest and providing further details (see Figure 2).

Our final best practices question, How can we develop culturally appropriate research protocols?, is of utmost importance to our team. We aim to conduct rigorous research that will yield knowledge that is useful and actionable to those directly concerned with the health and wellbeing of youth in Sa-

linas and similar agricultural areas. It is therefore tremendously important that youth and their parents feel comfortable with, and preferably enthusiastic about, participation in the study. To this end, the A Crecer team actively solicited and incorporated information regarding local culture, terminology and norms to inform recruitment and interviewing procedures for the cohort study. We drew heavily on the knowledge and insights of the Salinas-based staff members, led by the Project Coordinator, particularly regarding how to best approach youth and their parents about study participation. Staff framed the study as exploring 'what it is like to be a teen in Salinas', and encouraged students to consider participating as a way to 'share your voice' and contribute to the community. The staff also noticed that peer leaders could quickly set the tone for whether youth would express interest in study participation, and they consciously adopted strategies of 'matching the tone' of exuberant students, generating a sense of shared enthusiasm, while also telling students that they could join the study with friends and come to interview appointments together. As recruitment proceeded, the staff noted that they had developed ways of adjusting recruitment to different environments (schoolyards vs classrooms), groups ('popular' kids as compared to quieter youth who kept to themselves) and even schools (noting that students in some schools wanted many details about participation, whereas in others the main focus was on concerns about confidentiality).

Early on in their recruiting, the Salinas-based staff discerned that both youth and their parents had concerns about what was meant by a 'research interview'. Realising that many people think of an interview in terms of what is seen on television news or talk shows, the staff began proactively explaining the quantitative interview more concretely. For example, they described the survey as 'multiple choice' and reiterated that youth could skip any questions they did not want to answer. They also specified that the answers were entered directly into a computer, which youth and parents alike found reassuring, often telling staff that they had been concerned that youth would be asked to write

down responses. These explanations also helped parents understand A Crecer as a research study, as opposed to an after-school program. In addition, the staff learned that parents were sometimes hesitant to enrol their children in A Crecer because they feared negative consequences for their child if they were unable to bring him or her to an interview appointment. The staff therefore made sure to explain to parents that children were never penalised for missing appointments. They also clarified that parents did not need to stay on site during the interview, recognising that many parents had multiple responsibilities and could not spare the time to wait. These efforts to assuage parents' concerns yielded not only higher numbers of enrolled study participants, but also a sense of pride among students and their parents who began to see study participation as a way of contributing to the community and benefiting youth. Building on this perspective, we partnered with local school officials to arrange for youth to receive community service hours for their participation in A Crecer.

Focus group findings also informed procedures for recruitment and obtaining parent permission for the cohort study. Based on parent feedback obtained through recruitment for the focus groups, the staff developed a telephone-based verbal parent permission process that ensured parents had opportunities to talk privately by phone and also to meet staff in person, either at our study office or at one of the five community-based interview locations, in advance of having their child enrol in the study. Concerns about literacy were also raised by youth during the focus groups, which confirmed our decision to use audio computer-assisted self-interviewing (ACASI) for the more sensitive questions, and staff emphasised during recruitment that youth were not required to read or write on their own in order to participate. Finally, we made use of multiple opportunities to build legitimacy within the community. For example, on two occasions, Salin-

as-based staff members were interviewed by a teen-led youth radio show that aired on a bilingual radio station as a means of raising awareness about the study and demonstrating engagement with the community.

Discussion

When conducting studies on SDH in communities that experience inequalities and marginalisation, researchers must be mindful of how the same conditions that may shape health disparities may also affect whether and how community members engage with research. We take A Crecer's ability to engage parents and school partners, achieve enrolment targets and sustain high retention to date as indicators that our approach has been successful, not only by research but also by community standards.

Importantly, this engagement has also helped us to ensure that our research focus is well aligned with parents' and youth's priorities and community objectives regarding the promotion of adolescent wellbeing. While A Crecer brings attention to challenges faced by youth in Salinas and an evidence base for tailored solutions to address these challenges, the study team has been cognisant of the potential for reinforcing a negative image of Salinas through the study findings. In focusing research on two of the most pressing public health problems facing Salinas teens (teen pregnancy and risk of violence), we have strived to also acknowledge the importance of understanding resilience among adolescents who are engaged in school, volunteer in a community to which they feel attached and are connected to families with whom they share strong bonds. It has been a priority of the A Crecer team to be vigilant about slipping into a problem-based characterisation of 'at-risk' youth in a disadvantaged community, and instead choosing to align with a growing movement to investigate what helps a community thrive, building on the strengths of its

residents and a proud cultural heritage. Collaboratively, the research team has challenged itself to incorporate protective factors such as school connectedness, resilience and a future orientation towards the measures of influences that lead to a positive trajectory. This focus grew naturally out of the strong community-research linkages forged by intentional community engagement during the formative stages of the study. This more balanced approach respects and nurtures growing community pride and has been welcomed by CAB members, YAB members and local stakeholders.

Our team is fully committed to the approach described in this article. We recognise that such engagement requires time, resources and a willingness of all parties to listen, be transparent and remain open-minded. It has been important – and meaningful – in A Crecer for the San Francisco-based researchers to spend entire days in Salinas in an effort to better understand the context in which the study takes place, meet face to face with community partners and problem-solve on site with the local staff. Likewise, the Salinas-based research staff have worked evenings and weekends in order to maximise their ability to connect with parents, teachers and other community members, shared their observations and experiences in order to inform the aspects of the research that can be adapted to the local culture, and maintained the research protocols that need to be standardised with equanimity and good humour. Within a study that focuses on rural Latino youth, many of whom contend with immigration, acculturation, poverty and other issues that could potentially affect health outcomes, such efforts to create community-level trust and buy-in are key conditions for the production of high-quality data that can be used to support resources, solutions and paths forward.

Conclusion

Work that will meaningfully affect SDH must be conducted in ways that not only acknowledge community challenges but also recognise and build upon resilience. Taking this approach promotes a growing communi-

ty awareness of the barriers resulting from SDH and the drive to address these factors to further the development of a safe and thriving community. In the case of our research with rural Latino youth, building in the active participation of the actors in charge of the settings where adolescents live, such as educators and parents, was crucial. Indeed, developing these community partnerships and working to maintain them through accountability and transparency helped expand the reach of our study to a greater number of residents, thereby promoting community engagement and expediting participant recruitment. Likewise, we found that by engaging local opinion leaders – including youth – early in the research process, support for the study spread through multiple channels, minimising the barriers that could have arisen for community members who feel wary of outsiders and instead prompting parents to come forward and enrol their children in what was perceived as a positive community-focused activity.

Despite their importance, building community partnerships and providing avenues to hear the voices of a study population is not sufficient. In order for research among vulnerable groups to be as relevant and ethical as possible, community perspectives and expertise must be deeply integrated into the study itself. Two channels for this are research staff and protocols, the heart and soul of a study. By hiring young people from the local community and valuing and building their knowledge, we hope not only to improve the quality of our current work, but also to help train the next generation of scholars. Similarly, by designing protocols that are culturally appropriate and respectful, we aim to broaden the community's understanding of research, degree of comfort engaging with it, and expectations that it should lead to solutions that will be feasible and effective. In working towards these goals, we hope that A Crecer will live up to its namesake by providing opportunities not only to learn, but for all of us involved – youth, community and researchers – to grow.

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